

Wednesday, July 14, 2004

David R. Baker
Senior Web Content Account Manager for the ODPHP
U.S. Department of Health and Human Services
200 Independence Avenue SW, Room 625E
Washington, DC 20201

Dear Mr. Baker,

Thank you for your timely response to my query of July 2, 2004

I hope to accomplish several things by means of this correspondence. In the first place, I will request specific information from you, the ODPHP and the NCHI regarding your healthfinder® Website selection process and personnel. Secondly, I will respond to the general comments in your message. Thirdly, this letter constitutes a formal complaint with regard to healthfinder® violations of HONcode principles. Finally, this letter constitutes submission to your office of "an information request for [review and] correction" as specified in the HHS "Guidelines for Ensuring the Quality of Information Disseminated to the Public" at <http://www.hhs.gov/infoquality/os.html#oig>. The remedy I seek is the de-listing from healthfinder® of the "CAM"-promoting organizations and Websites I cite that fail to meet published healthfinder® selection standards, and the inclusion on healthfinder® of the science-advocating "CAM"-oriented organizations and Websites I cite that do meet said standards.

In your message of July 7, you state that:

With regard to your comment concerning the National Council Against Health Fraud, we are aware of this organization and have determined that it should not be included in the healthfinder® Web site for a number of reasons.

I hereby formally request that you provide me with the following:

1. A list of the ODPHP and/or NCHI personnel you describe as "we" in the forgoing statement. I also hereby formally request a list of past and present members of healthfinder®'s Steering Committee, whether or not said list is identical to the aforementioned list/group.
2. A complete list of any and all the individuals responsible for the decision to exclude or remove any or all of the following organizations and Websites from healthfinder® Website:

Quackwatch (<http://www.quackwatch.org/index.html>) (An HONcode approved site)

The National Council against Health Fraud (NCAHF) (<http://www.ncahf.org/>) (An HONcode approved site)Chirobase (<http://www.chirobase.org/>) (An HONcode approved site)Robert

Carrol's Skeptical Dictionary of Alternative Medicine
(<http://web.archive.org/web/20021015210234/skevdic.com/tialtmed.html>)

3. A list of any credentials and - specifically -- any publications, educational or clinical experience, employment or business/commercial affiliations said individuals may have cited as qualifications for their inclusion in the decision-making process with regard to "CAM" organizations and Websites considered for inclusion/exclusion on the healthfinder® Website.

4. A complete copy of the minutes from the meeting(s) wherein you and/or your colleagues discussed these issues and decided to exclude the Quackwatch, the NCAHF and the other aforementioned organizations/Websites from the healthfinder® Website (or decided to terminate their prior listing on same).

Thank you in advance for your cooperation in this matter.

Secondly, your healthfinder® Website prominently displays the HONcode (Health on the Net) logo and claims "we subscribe to HONcode principles of the HON Foundation." See: <http://www.hon.ch/home.html>. This claim is not supported by the facts. Your Website violates HONcode principles on many counts.

This letter constitutes a formal complaint to you, and to the HHS, Office of Disease Prevention and Health Promotion regarding said HONcode violations of principle. It also constitutes a formal complaint to the Health on the Net Foundation (HON) itself. As per HONcode "policing" policy - I will both address the various general comments you made in you previous letter and offer specific, objective information demonstrating exactly how and why the specific healthfinder® listed Websites I've cited violate HONcode principles. See <http://www.hon.ch/HONcode/policy.html> and <http://www.hon.ch/HONcode/Conduct.html>

What follows are my responses to your general comments of 7-7-04. I have included a more comprehensive list of healthfinder®-approved Websites and organizations, along with links to information challenging or refuting their suitability for inclusion, as an appendix at the end of this letter.

You state:

Most of the organizations that you cite in your email are national professional associations of licensed health care practitioners in the field of complementary and alternative medicine (CAM) .

According to a recently released study by the National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health, 36 percent of U.S. adults aged 18 years and over use some form of complementary and alternative medicine [<http://www.nccam.nih.gov/news/camsurvey.htm>, May 2004].

The fact is that another recent study of roughly equal size has reported far less widespread usage and popularity for alleged "CAM" therapies than the NCCAM-funded study you cite.' In any case, it sounds as though you're suggesting that unproven, disproved and/or irrational "alternatives" to scientific biomedicine are worthy of promotion on your healthfinder® Website merely because they enjoy some arbitrary level of popularity. Is that the case?

It's worth noting the various ways in which the NCCAM-funded study you cite manipulates language so that it casts scientific biomedicine in an unjustifiably negative light and alleged "alternatives" in an unjustifiably positive light. To cite just one example out of many, in the introduction, the study refers to science-based medicine as "conventional" and "western" and then goes on to speculate as to why "CAM" users are "dissatisfied" with same.

In the first place, referring to scientific biomedicine as "conventional" or "western" tends to provincialize and trivialize it as "just one medical system among many equals." Scientific biomedicine isn't "western" any more than it's "southern" or "northern." It may have arisen in the West, but it has long since become universal. Contributors to, and innovations in scientific biomedicine come from every race, every gender and every corner of the world. It has no "equals" when it comes to proven efficacy and safety. Secondly, the assertion that "CAM" users are "dissatisfied" with "conventional medicine" is contrary to the best available evidence.' The great majority of such individuals employ "CAM" therapies *in addition* to science-based therapies.

The authors immediately go on to assert that "this dissatisfaction may be related to the inability of conventional medicine to adequately treat many chronic diseases and their symptoms such as debilitating pain." They avoid mentioning that, to date, there is no compelling scientific evidence that *any* "alternative" therapy has specific "above placebo" efficacy *at all* in the treatment of debilitating pain or *any* chronic disease. Their assertion falsely implies that scientific biomedicine has been largely ineffective in the treatment of chronic pain and many chronic diseases when the opposite is true. Scientific biomedicine has, in fact, developed many effective means of treating debilitating pain and various chronic diseases, and new and ever-more effective interventions are constantly emerging.

I provide additional information documenting the consistently "promotional" nature of the NCCAM and the various studies it has funded in the appendix to this letter.

You state:

healthfinder.gov®'s CAM selection policy focuses primarily on national professional associations, as well as educational, accreditation, and licensing entities, with

You are mistaken when you assert that most of the organizations I cited are associations of "licensed health care professionals." Most involve primarily *unlicensed* practitioners. Naturopaths are currently licensed in only eleven out of fifty states and homeopaths are licensed in only three states. Currently, no state specifically licenses reflexologists, aromatherapists, meditation therapists, or environmental therapists.

In any case, even for those alleged CAM modalities that do enjoy licensure, the healthfinder® recommended sites and organizations I cited are *not*, themselves, so licensed or recognized. Also, there is no such thing as a legitimate or discrete "field" of "alternative and complementary medicine" - at least not in the sense that there are "fields" within scientific biomedicine. If you feel there is, please cite the underlying physiologic laws and universal scientific principles that are common to all CAM modalities. The only thing *truly* common to all alleged CAM therapies is that they are either untested, irrational, or have already been studied and disproved and therefore - of necessity - have been rejected by science-based medicine. (A few candidates - such as massage, diet modification, relaxation techniques and so on - have actually been an ancillary part of mainstream medical therapy for decades or centuries, and are therefore not legitimately "alternatives" to same.)

The largely meaningless definitions of "CAM" adopted by the NCCAM and other "CAM"-promoting organizations tend to be strictly negative: CAM therapies are defined as those therapies that are *not* generally taught in medical schools, are *not* mainstream, and so on. This makes roughly as much sense as attempting to define a "dog" as "not a cat." One recent study observed: "there is no consensus in the scientific community as to which therapies should and should not be considered unconventional. The original definition (lack of inclusion in medical schools or availability in U.S. hospitals) has become a moving target [...]"¹

In any case, your claim (that "most of the organizations [in question] are national professional associations of licensed health care practitioners) is irrelevant. The healthfinder® Website is funded by the ODPHP, Office of Public Health and *Science*. The latter takes pride in "working to strengthen the disease prevention and health promotion priorities of the Department within the collaborative framework of the HHS agencies." I fail to see how providing false, distorted, unbalanced, misleading, and anti-scientific medical information offered by unlicensed *or* licensed aromatherapists, homeopaths, chiropractors, naturopaths or reflexologists "works to strengthen disease prevention and health promotion priorities" in the eyes of a federal department supposedly dedicated to public health and *science*. How can promoting such medical misinformation reasonably be construed as being of benefit to U.S. health care consumers?

It seems to me that you and healthfinder® are attempting to dodge responsibility for genuinely examining the scientific validity and reliability of the sites you promote by hiding behind the demonstrably false assertion that "if they're licensed or embraced by a 'respected institution,' they must be scientifically legitimate." This, in my view, constitutes a gross failure of responsibility on the part of a U.S. government department funded by taxpayer dollars and entrusted with protecting the public interest.

You state:

the goal of directing consumers seeking CAM to licensed practitioners operating legally under applicable state laws and providing information concerning the processes by which they are trained and licensed so that consumers can find a reputable practitioner and determine his or her credentials.

I should imagine that finding a "reputable" or "reliably trained" reflexologist or holistic aromatherapist must be akin to finding a "reputable" and "reliably trained" astrologer or numerologist. Exactly what standards did you and your staff employ? I assume you can answer this simple question in view of the fact that the Reflexology Association of America and the National Association for Holistic Aromatherapy are both sites promoted on healthfinder®. I would very much like to know how you and your staff determined that the reflexologists and aromatherapists maintaining and/or belonging to these organizations are reputable and reliably trained.

You attempt to justify inclusion of a disparate hodge-podge of thoroughly uncritical "CAM"-promoting Websites and the exclusion of virtually all science-based and non-promotional websites critical of CAM claims on the basis that "healthfinder®'s CAM selection policy focuses primarily on national professional associations, as well as educational, accreditation, and licensing entities." Unfortunately, the facts don't bear out this claim.

In the first place, both Quackwatch and the NCAHF are nationwide organizations. They both provide an enormous assortment of factual, accurate, well-documented and science-based educational material in the form of articles, editorials, newsletters, Internet lists and position papers. They have both sponsored and/or supported science-based educational conferences. They both are operated and supported on a not-for-profit basis largely by degreed health professionals and degreed scientists, educators and science-advocates (in addition to consumer advocates.)

Few if any of the organizations listed in the appendix to this letter, all of which are promoted on healthfinder®, can legitimately make the same claims. Only a tiny minority of them are accredited by national or state educational accrediting agencies. None of them are government-recognized licensing agencies.

So, why are these sites promoted on healthfinder® when the Quackwatch, the NCAHF and various other science-based but critical-of-"CAM" sites are excluded from same?

The people you describe as "seeking CAM" are, in my view, much more in need of accurate information regarding the alleged "alternative therapies" they're seeking than they are of finding a practitioner who enjoys scientifically meaningless "licensure" or "accreditation" in same. The last thing they need is a recommendation from a Website -- supported by taxpayer dollars -- that uncritically guides them in the direction of a medical intervention that's, at best, of no proven utility, or more likely disproved, irrational and financially wasteful.

The fact is that, currently, healthfinder® is not living up to its own, published, selection standards. See: <http://www.healthfinder.gov/aboutus/selectionvolicity.htm>. The published

standards state that "organizations should provide a substantial amount of consumer health information as part of their mission, and that information should be current, consistent with basic science and recommendations of recognized authorities, and well-designed." The CAM-promoting organizations and Websites I list in the appendix to this letter *do not* present information that is "current, consistent with basic science and recommendations of recognized authorities." Moreover, the alleged "consumer health information" these sites provide tends to be either largely false, inaccurate or highly distorted in favor of the alleged "alternative" they are promoting. I will deal with these issues on a point-by-point basis later.

You state:

As a medical professional, you are no doubt aware that most aspects of the licensing and regulation of the health professions are state government functions. CAM licensing varies by state, but the majority of states do license CAM practitioners.

These statements are both irrelevant and misleading. As I pointed out earlier, most states *do not* license naturopaths or homeopaths and *no* state currently licenses reflexologists, aromatherapists, meditation therapists, or environmental therapists. Only subluxation-based chiropractors, among pseudoscientific practitioners, enjoy universal licensure in the U.S. (On the other hand, chiropractors enjoy a much lower incidence of licensure internationally.)

In any case, on what basis have you, your department, or the NCHI, decided that health care professionals and consumers need to be directed to sites promoting inaccurate and unreliable medical information merely because some practitioners of same have been "licensed" or "accredited"? While it's true that the U.S. Department of Education recognizes agencies that accredit schools of chiropractic, cosmetology, Biblical higher education, acupuncture, dance, naturopathy, pastoral education, theater, theology and other such fields, it does so *without* regard to the scientific validity of the material these schools teach. See: <http://www.ed.gov/print/admins/finaid/accred/accreditation.html>. Likewise, state accrediting and licensing agencies tend to employ strictly *non-scientific* standards when considering accreditation of unscientific and pseudoscientific modalities and practitioners.

On the other hand, all of the health care professionals and individuals operating and maintaining Quackwatch and the NCAHF have been licensed by appropriate government agencies, yet the organizations are denied inclusion by healthfinder®. Again, how do you rationalize the double standard?

As a medical professional, I am aware that licensing and credentialing of practitioners of unproven, disproved, unscientific and/or irrational therapies does little if anything to protect the interests of health care consumers. (See: Problems with "CAM" peer-review and accreditation, <http://www.quackwatch.org/04ConsumerEducation/peer.html>). Such licensure serves primarily the interests of just two entities: politicians/bureaucrats who wish to create the false impression that they are "doing something pro-active to protect the public," and the dubious practitioners, themselves, who crave the "political legitimization" such licensure affords them in the eyes of a naive public. This is particularly important in view of the fact that most so-called CAM

therapies in question have repeatedly proven incapable of attaining legitimate scientific validation on their own merits. I'm also aware of the fact that most states grant licensure and/or accreditation for "alternative" practices and practitioners without *any* consideration for the scientific validity of -- or evidence for efficacy of -- the "therapy" in question.

As just one possible example out of many candidates, consider subluxation-based chiropractic. In the roughly 110 years since D. D. Palmer invented this "therapy," no one has ever been able to develop a shred of credible scientific evidence for the existence of chiropractic subluxations. Yet, subluxation-promoting chiropractors are licensed by the tens of thousands in the U.S., and they charge naive health care consumers billions of dollars every year to "adjust" their indistinguishable-from-imaginary subluxations. Every year, in addition to wasting a great deal of money, people suffer strokes, other injuries, and even death, at the hands of "licensed" chiropractors seeking to treat the medical unicorns they deem "subluxations." (See: http://www.quackwatch.org/Ol_OuackeryRelatedTopics/chirostroke.html) Of course, you might not be aware of these "negative facts" regarding chiropractic, because healthfinder® has chosen to systematically exclude and ignore all such negative factual information as well as Chirobases's referral directory of chiropractors who engage in science-based practice.

You state:

With regard to your comment concerning the National Council Against Health Fraud, we are aware of this organization and have determined that it should not be included in the healthfinder® Web site for a number of reasons. The primary reason is that the mission of the healthfinder® Web site differs from that of the NCAHF--our site focuses on providing quality information about general health issues from government and nonprofit sources, a 'whitelist' as opposed to a blacklist.

If the "primary reason" you have excluded the NCAHF from healthfinder® is that its "mission differs from yours," then surely it follows that the missions of the various reflexologist, acupuncturist, aromatherapist, chiropractor, and homeopathic organizations you list and promote are the same as yours. Is that the case?

The real problem here seems to be that you and your colleagues are "picking and choosing" which of the published healthfinder® selection standards you will employ, and which you will ignore. You also seem to be making up a few new standards "on the fly." See <http://www.healthfinder.gov/aboutus/selectionpolicy.htm>. Here are a few of the published standards you have apparently decided to ignore in your selection process:

- 1.1 The goal of the Web site is to improve consumer access to selected health information from [...] *reliable sources* that *serve the public interest*. (The pro-"CAM" sites on healthfinder® do not live up to any reasonable standard in this regard. Quackwatch, the NCAHF and the other skeptical-of-"CAM" organizations and Websites I've cited *do* meet a very high standard in this regard.)

- 1.3 *"Credible Organizations:* In the healthfinder® selection process, each organization is reviewed to establish its **general reliability and credibility...**" (Exactly how did you review and establish the general reliability of the aromatherapy, homeopathy, reflexology, acupuncture and naturopathy sites you selected for inclusion on healthfinder®? Again, I request a copy of the minutes of the meetings during which such general reliability was established by you and your colleagues at healthfinder®. Quackwatch has won more than 70 awards and honorable mentions, including endorsements from JAMA, Forbes Magazine and Encyclopedia Britannica. In addition, last year it won a national award for the best individually run Web site based on a poll of professional readers of a medical Internet magazine (MD Netguide) for physicians. The NCAHF has also been the recipient of various honors on the basis of quality and reliability.)
- 1.8 *"Characteristics of Organizations Reviewed...* The organizational characteristics commonly assessed in these selection processes include - [...] **Quality of the information and services provided.**" (Exactly how did you determine that the quality of the information provided by the aromatherapy, homeopathy, reflexology, acupuncture and naturopathy sites you selected for inclusion on healthfinder® was sufficient to meet your standards? On what basis did you determine that the quality of the information presented by Quackwatch, the NCAHF and the other skeptical-of-"CAM" organizations and Websites I've cited is not up to healthfinder® standards?
- 3.4 The organizational characteristics assessed in the selection process include the following: [...] Organizations should provide a substantial amount of consumer health information as part of their mission, and **that information should be current, consistent with basic science and recommendations of recognized authorities**, and well-designed. (None of the pro-"CAM" healthfinder® Websites I have cited in the appendix to this letter live up to this standard. What do you feel is the "basic science" behind aromatherapy, homeopathy, reflexology, acupuncture and/or naturopathy? Whom do you feel are "recognized authorities" in these pseudoscientific fields? ...And by **whom** are they recognized.? Quackwatch, the NCAHF and the other skeptical-of-"CAM" organizations and Websites I've cited **do** live up to this standard.)
- 3.5 Each organization will be evaluated according to published information (primarily Web site) as to its adherence to general standards for **quality of health information** on the Internet, including [...] currency and **scientific accuracy**. (The pro-"CAM" sites on healthfinder(g do not live up to any reasonable standard in this regard. Quackwatch, the NCAHF and the other skeptical-of-"CAM" organizations and Websites I've cited **do** meet a very high standard in this regard.)
- 3.7 *Balance of the Collection:* [...] The total number of Web resources selected for any given topic should be the minimum number that can present **a complete picture of the topic** (This directly contradicts your assertion that healthfinder® is obliged to link only to "white list" Websites that promote alleged "alternatives" and to reject "black list" sites that publish factual, but "negative," material relative to same. Where is the "balance" in such a policy? How can healthfinder® be presenting a "balanced picture of the topic" if

it refuses to link to any Websites expressing generally negative, well-documented views of "alternative" therapeutic claims and beliefs? By what authority have you and your ODPHP/NHIC colleagues chosen to ignore this "balance" requirement as set out in your published standards? Again, I hereby request to see the minutes of the meeting(s) wherein this issue was discussed and decided.)

Finally, please note that the printed healthfinder® selection standards include the following:

- 3.5 *"Evolving Standards for Information Quality on the Internet: [...]"* Examples of evolving standards include [...] White Paper: Criteria for Assessing the Quality of Health Information on the Internet (<http://hitiweb.mitretek.org/docs/criteria.ndf>). (It is interesting to note that one of the five authors of this 1997 White Paper, to which healthfinder® ascribes, was the late John Renner, MD. ***John Renner was president of the NCAHF at the time this document was written.*** So it would appear that the National Council Against Health Fraud played a significant, if indirect, role in the development of the nascent healthfinder® Website's standards for selection. Yet, oddly, it is your position that the NCAHF does not meet requisite standards for inclusion on the healthfinder® Website.)

With regard to your assertion that you only want to present "whitelists" rather than "blacklists" regarding "CAM" Websites on healthfinder®, I can find no provision in your own published standards suggesting such conditions for acceptance or rejection. How did you and/or your colleagues at the ODPHP and/or the NHIC come up with such an "additional" standard?

You state:

Your list also includes federally funded CAM research centers at two prestigious universities and the White House Commission on Complementary and Alternative Medicine. This is public information concerning U.S. government activities, and so is appropriate for inclusion on our Web site.

None-the-less, these entities have consistently provided demonstrably false, inaccurate, misleading, unbalanced and highly promotional material dealing with alleged "CAM" modalities. From healthfinder®'s perspective, shouldn't that count for more than the alleged "prestige" these organizations enjoy? Shouldn't these entities *also* have to live up to all the *other* healthfinder® standards for inclusion?

Subsidizing sub-standard, pseudoscientific, and ideologically/politically motivated medical research should, in fact, serve to tarnish the "prestige" and "respect" afforded the governmental and educational institutions involved. It's absurd to suggest that the process should work in reverse to enhance the standing of the sub-standard research.

With regard to the White House Commission on CAM, the words of two dissenting commission members (buried in a brief "Appendix G" to the WHCCAM report) are quite revealing: "many of the Commission's recommendations [...] do not appropriately acknowledge the limitations of

unproven and unvalidated `CAM' interventions or adequately address the minimization of risk. [...] This advocacy tone persists in the Report despite great efforts to achieve editorial balance. Despite qualifying statements added to the Introduction of the Report -- which we endorse -- the body of the document continues to give voice to a perspective that suggests that most "CAM" interventions will be proven to be safe and effective through scientific research." I've provided links to even more damning information in the attached appendix.

What I find most troubling about healthfinder®'s (and presumably the ODPHP and NHIC's) selection policy is that you and they seem to be applying a separate standard for accepting these and other pro-"CAM" Websites and organizations - and it's clearly a much lower standard than you've applied to Websites and organizations critical of "CAM" claims. The published healthfinder® selection policies specify that candidate Websites and organizations "should meet all criteria for inclusion." It seems to me that you have consistently and systematically failed to meet this standard - both in routinely accepting Websites and organizations that falsely promote "CAM" and in routinely rejecting Websites that rationally criticize "CAM" claims. The mere fact that false and misleading "CAM" information comes from "prestigious universities," "federally funded organizations," a "White House Commission" a strictly "white list" source or "a national association of licensed professionals" should not, in and of itself, constitute sufficient justification for inclusion on the healthfinder® Website.

Again, I hereby request that healthfinder® review the situation I've outlined. The remedy I seek is the de-listing those "CAM"-promoting organizations and Websites I've described that fail to meet published healthfinder® selection standards, and the inclusion on healthfinder® of the science-promoting organizations and Websites I've described that do meet said standards.

Sincerely,

CC: Rachel Langston, National Health Information Center (NHIC)
Health On the Net Foundation
Tommy G. Thompson, Secretary of Health and Human Services
Rear Admiral Christina Beato, MD, Acting Assistant Secretary of Health
John Jarman, Executive Director, Office of Public Health and Science
Capt. Penelope Royall, P.T., M.S.W., Director, ODPHP
Dara Corrigan, Acting Principal Dep. Insp. Gen., Office of Inspector General, DHHS
Gunther Eysenbach, M.D., M.P.H., Editor, Journal of Medical Internet Research (JMIR)
Paul Kurtz, PhD, Council for Media Integrity
Rep. James A. McDermott, MD, Ways and Means Subcommittee on Health
Sen. William H. Frist, MD, Senate Majority Leader, HELP Committee